



CHAPTER 5: CAPACITY, SEXUALITY & FAMILY LIFE

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As people with intellectual disabilities increasingly live in inclusive community environments, they have greater opportunities to develop friendships, engage in sexual relationships, marry, and bear and raise children. The issue of capacity to consent lies at the heart of these often complex issues.

I. CAPACITY AND MARRIAGE

Although historically many states prohibited people with intellectual disabilities from marrying, this is no longer the case. But, this does not mean that people with intellectual disabilities have an absolute right to marry.

In Pennsylvania, the law provides that marriage licenses -- a prerequisite to statutory marriage -- cannot be issued "if either of the applicants for the license is weak minded, insane, of unsound mind or is under guardianship as a person of unsound mind unless the court decides that it is for the best interest of the applicant and the general public to issue the license and authorizes the issuance of the license." Accordingly, a marriage license technically may be denied to a person with an intellectual disability who either has a guardian or who is considered to be of "unsound mind."

Individuals with intellectual disabilities, however, have been able to obtain marriage licenses and to marry in Pennsylvania. Even when license applications are initially rejected, courts have authorized the issuance of licenses for such individuals.

Although Pennsylvania marriage law indicates that persons "under guardianship" cannot secure marriage licenses without court approval, Pennsylvania's guardianship law does not authorize a guardian -- even a plenary guardian of the person -- to prohibit the marriage of the individual who has been adjudicated incapacitated. A guardian of the person can secure the right to prohibit marriage by an incapacitated person only after the court holds a hearing on the specific issue, makes express findings of fact, and issues an order that addresses the issue explicitly.

II. CAPACITY AND SEXUALITY

Many people with intellectual disabilities want to have and do have relationships that include sexual expression. Yet, at the same time, it is important to recognize that some individuals with intellectual disabilities are particularly vulnerable to sexual exploitation and abuse. Indeed, people with intellectual disabilities are subject to sexual violence at higher rates than others. The ability of a person with an intellectual disability to participate in sexual activities with another person, however, will depend on his or her social understanding and capacity to consent to such activities.

Appropriate sex education can be a key to providing individuals with intellectual disabilities with the capacity to engage in voluntary sexual activities if they choose, to prevent sexual abuse or exploitation, and to understand appropriate sexual boundaries and behavior to prevent the possibility that they may face criminal charges.

A. Sex Education

It is important for individuals with intellectual disabilities to have access to meaningful, comprehensive sex education. For all people, regardless of disability, education helps to eliminate the vulnerability caused by ignorance, empowers individuals to make informed choices, enables them to recognize and report abuse, and enhances their capacity to express their sexuality in appropriate ways.

Sex education is particularly important to individuals with intellectual disabilities. These individuals may not have access to or be able to take advantage of the other resources through which people can informally learn about sexuality and its proper expressions. Difficulties reading may limit their ability to get information from books or other written materials. Their friends may not have much more knowledge about sex than they do.

There may be few opportunities for them to observe, model, and practice appropriate behaviors. Due to the lack of these positive sexuality supports and education, individuals with intellectual disabilities may express their feelings in ways that others may deem inappropriate, or out of place for a given situation or location.

Sex education also provides people with intellectual disabilities with the information and language they need to recognize, prevent, report, and avoid sexual abuse and exploitation. Education can help individuals understand the difference between consensual sexual acts and sexual abuse. Education can also help individuals to overcome low self-esteem that might lead them to accept sexual advances from people who want to

exploit them. Education additionally can provide them with the understanding that they have the right to say "no."

The goals of sex education for people with intellectual disabilities thus should include:

- providing them with the language resources they need to discuss sex (including anatomy and physiology);
- providing information about forms of romantic and sexual expression;
- teaching about the importance of privacy;
- understanding different types of relationships and what forms of contact or interaction might be appropriate;
- teaching and reinforcing good social skills in both public and private settings;
- providing information on the consequences of sex and how they can be avoided, including unwanted pregnancies and sexually transmitted diseases;
- helping them to understanding and avoid sexual abuse and exploitation and how to report it;

- helping them to reach their own understanding of what role they want sex to play in their lives in light of their own values.

There are various training techniques and curricula that are available (e.g., a "buddy system" that links a student with an intellectual disability with another student who can help teach routine interactions; rehearsal and role playing techniques that allow individuals to practice how they would behave in different situations; positive behavior supports to reward appropriate behavior). Of course, each individual with intellectual disabilities will have his or her own unique learning needs, and the program of sexual education should be adapted to best meet those needs.

In addition to school-based sex education, families and caregivers can play important roles, too. For instances, families can use "teachable moments" - from a couple kissing or a wedding or a new baby or a storyline in a television show -- to discuss sexuality informally but with honesty, providing their own views but encouraging the individual to express his own views and to ask questions. Families and caregivers should also encourage their loved ones to ask questions and not react to questions judgmentally or critically. Families and caregivers can reinforce their own beliefs and society's beliefs of what sexual behavior individuals should conduct in private and what is acceptable in public. Perhaps most importantly, families and caregivers should facilitate the participation of the individual in community activities that give them a wide range of experiences and that enable them to have frequent and diverse social interactions and relationships.

B. The Absence of Consent

In Pennsylvania, sexual contact with an individual who has a mental disability which renders the individual incapable of consent constitutes a criminal act that can be prosecuted. It is not necessary to show force was involved; the absence of capacity to consent due to a mental disability can establish criminal liability. Thus, there are serious legal ramifications for sexual activity with an individual with an intellectual disability who cannot give consent.

Neither Pennsylvania's criminal statutes nor the case law clearly define how to measure whether a person with an intellectual disability is capable of consenting to sexual activity. Consent likely will be determined by assessing whether the individual: understands the nature of sexual contact; understands and is able to exercise the right to refuse the activity; and is familiar with the possible risks and consequences of the activity. In one Pennsylvania case, for instance, the court upheld a rape conviction of a man who had sex with a woman with an intellectual disability who had been babysitting his child. The court credited the testimony of an expert that the woman was incapable of consenting to sexual intercourse because she had an IQ of 58, behaved in a manner "similar to that of a child," had limitations in her daily life, did not have good judgment, was highly influenced by others, and was not able to understand the consequences of her actions.

Often, as in the case discussed in the prior paragraph, professionals will be required to interview the alleged victim to determine if he or she was

capable of providing consent to sexual activity. Several authors have identified a number of specific issues that should be considered in making that assessment, including:

- Does the person have an awareness of people, time, places, and events?
- Does the person have basic knowledge of sexual activities?
- Does the person know how to safely participate in sex (e.g., using birth control)?
- Does the person understand the physical consequences and legal responsibilities of pregnancy?
- Is the person aware of sexually transmitted diseases and how to avoid them?
- Does the person understand that they can say "no"?
- Is the person able to call for help or report unwanted sexual advances or abuse?

All individuals are unique and should have the right to assume certain risks, including those relating to their choices regarding sexuality. It is the individual's role to make informed and personal choices about sexual

activity in light of his or her own values and abilities. The law, though, does balance the individual's right to control of his or her own body and sexuality against the need to protect the individual from harm.

III. CAPACITY AND REPRODUCTIVE RIGHTS

Generally, people with intellectual disabilities should have the same legal rights to make their own decisions about procreation. Optimally, this decision would be made by each individual with intellectual disabilities, after receiving appropriate sexual education and consulting with his or her sexual partner, family, and a support team and would be based on the individual's personal values, realistic expectations and goals, and consideration of resources and potential legal issues. Questions of capacity, though, can affect the reproductive rights of people with intellectual disabilities. Specifically, the rights of individuals with intellectual disabilities to control their own bodies and make their own reproductive choices can be limited through non-consensual sterilization and limits on access to legal abortion based on the lack of capacity of the individual.

A. Sterilization

Non-consensual sterilization of individuals with intellectual disabilities cannot be authorized by family or providers. Court-appointed guardians also do not have authority to consent to the sterilization of a person who has been adjudicated incapacitated, unless the guardian petitions the court to allow the guardian to consent to the sterilization of the incapacitated person.

Courts can authorize guardians to consent to involuntary sterilization only after a hearing has been held on that specific issue and the court makes specific findings of fact that supports the decision. Since sterilization results in permanent termination of the right of procreation, the Pennsylvania courts will authorize sterilization only if they determine that it is in the best interest of the individual. Courts will look at a number of factors in reaching that decision, including:

- whether the person lacks capacity to make a decision about sterilization and whether that incapacity is unlikely to change in the future;
- whether the person is capable of having children;
- the likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual activity is forced upon him or her;
- whether sterilization is the only practicable means of contraception and that all less drastic contraceptive methods, including supervision, education, and training, are unworkable;
- whether the individual will experience trauma or psychological damage if she becomes pregnant and gives birth or if he fathers a child;

- whether the individual will experience trauma or psychological damage if he or she is sterilized;
- the possibility that the individual will at some point marry and, with a spouse, be able to care for a child;
- the inability of the person to care for a child;
- whether the guardian is acting in good faith and that his or her primary concern is for the best interest of the individual rather than his or her own or the public's convenience.

Individuals with intellectual disabilities whose guardians seek sterilization orders must be provided with court-appointed legal counsel (unless they already have an attorney to represent them) to defend their interests at the hearing. The court also should interview the individual involved to assess his or her physical and mental condition and allow them to express their own views on the subject. An individual's opposition to sterilization should weigh heavily against court authorization of the procedure.

B. Abortion

Generally, a woman with an intellectual disability should be able to make the same decisions about whether to terminate a pregnancy as a woman without a disability. Women with intellectual disabilities who have guardians, however, may see those choices restricted.

Under the "parental notification" provision of Pennsylvania's Abortion Control Law, a woman who has been adjudicated to be incapacitated and has a court-appointed guardian generally cannot choose to terminate a pregnancy without notifying her guardian, just as a minor is required to notify her parents. A woman who has been adjudicated incapacitated, however, can opt to seek a court order to authorize the abortion if: (1) either the woman's guardian refuses to consent or if she chooses not to seek the guardian's consent; and (2) the court, after a hearing, determines either: (a) that the woman is mature and capable of giving informed consent and does in fact consent to the procedure, or (b) the woman is not mature and able to give informed consent, but an abortion would be in her best interests.

On the other hand, a woman who has been adjudicated incapacitated and who does not want to terminate her pregnancy has greater protections. Under Pennsylvania's guardianship law, a guardian cannot consent to the abortion for a person who has been adjudicated incapacitated without getting specific court approval for the procedure after the court holds a hearing and makes specific findings of fact. Moreover, it is arguable that courts do not have the power to authorize guardians to consent to terminating the pregnancy of an incapacitated person over her objection since Pennsylvania's Abortion Control Law provides that guardians cannot coerce persons who are incapacitated into having abortions.

IV. CAPACITY AND CHILD-REARING

All parents -- including those with intellectual disabilities -- generally have the right to raise their own children as they see fit. This right, however, is not absolute. When parents, including those with intellectual disabilities, are unable to provide for the needs of their children, their right to retain custody may be jeopardized and, eventually, they may be faced with the termination of their parental rights.

Under Pennsylvania's Juvenile Act, the Commonwealth can intervene with the rights of parents to raise a child if it believes that the child is "dependent." A dependent child is one who the court has determined does not receive proper parental care or control necessary for his physical, mental, or emotional health or morals. This can include:

- failing to provide the child with basic necessities, such as food, clothing, or shelter;
- failing to provide the child with supervision or discipline appropriate to the child's age and capabilities;
- financially exploiting the child;
- not assuring that the child regularly attends school;
- not providing proper medical care and treatment.

A child may not be removed from the family home before the court determines that the child is "dependent" unless it is determined that the

child should be taken into "protective custody" because there are reasonable grounds to believe the child is suffering from an illness or injury or is in imminent danger from his or her surroundings. The child can be held in protective custody for up to 72 hours. To hold the child for a longer period of time, the County Office of Children and Youth (OCY) must file a "shelter care" application, and a hearing must be held within 72 hours of the issuance of the protective custody order. Parents have the right to appointed counsel at the shelter care hearing if they are poor. At a shelter care hearing, the court will determine whether to maintain the child in an out-of-home placement or return this child to the home. The court will order the child to remain in an out-of-home placement if it finds that remaining in the home is contrary to the best interests of the child and that the County OCY made reasonable efforts to prevent the child's placement or that the lack of such efforts was reasonable. If continued out-of-home care is ordered, the County OCY must file a dependency petition within 24 hours.

Once a dependency petition is filed -- whether the child has been removed from the home or remained in the home -- the court will schedule an "adjudication hearing" to determine if the child is "dependent." Parents have the right to counsel at the adjudication hearing if they are poor. If the court determines that the child is dependent, it must schedule a "disposition hearing" to decide whether it is in the "best interests" of the child to permit him to remain in the family home with supervision by the County OCY and subject to conditions the court may set or to remove the child from the home and transfer temporary custody to a qualified individual, private agency, or public agency. The court can order removal only if there is "clear necessity" to separate the child from the parents and must consider whether

reasonable efforts were made to prevent placement. For children placed outside the home, the court will subsequently hold periodic "permanency review" hearings to determine the goals for the child (e.g., family reunification or adoption). Ultimately, the County OCY can file a petition to terminate the parent's rights if it concludes that adoption is the goal.

A child cannot be removed from the family home or adjudicated as "dependent" simply because one or both parents have intellectual disabilities. Nor can parents with intellectual disabilities have their parental rights terminated due solely to their diagnosis. On the other hand, a parent's diagnosis of an intellectual disability will not prevent the removal of his or her child, a dependency adjudication, or termination of parental rights if the parent is not able to meet the needs of the child due to the effects of the parent's disability.

Parents with intellectual disabilities should receive services and supports to help them to maintain their children at home. These services can include:

- "Services to Children in their Own Home" (also called SCOH services) are services that are made available to families to reduce the risk of abuse or neglect and to prevent out-of-home placement. SCOH services can include assistance with parenting and household organization, and medical, psychological, or other services or treatment;
- "Family Preservation" services that offer intensive, short-term, home-

based intervention to remedy problem situations and avoid placement;

- parenting classes;
- anger management classes;
- intellectual disability services through the Medical Assistance Waivers that can help support the family (e.g., homemaker or chore services).

It is imperative that parents with intellectual disabilities, their families, or advocates request these services through the County OCY or the County Intellectual Disability Program as soon as it becomes apparent that the parents are having difficulties. These services can help to prevent the removal of children from parents with intellectual disabilities and the termination of their parental rights.

Contact Information

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: intake@disabilityrightspa.org.

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